

This report contains the results of the Washington State Alzheimer's Disease Working Group Public Survey. Over 2,250 people responded, and indicated what they think is necessary to effectively address Alzheimer's and other dementias.

Alzheimer's Public Survey Results

Commissioned by the
Washington State Alzheimer's
Disease Working Group

Relevant Strategies, LLC February 15, 2015

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The Alzheimer’s Disease Working Group

In March 2014, Governor Jay Inslee signed [Senate Bill 6124](#), which provides legislative authorization to develop an Alzheimer’s Disease Plan for Washington State.

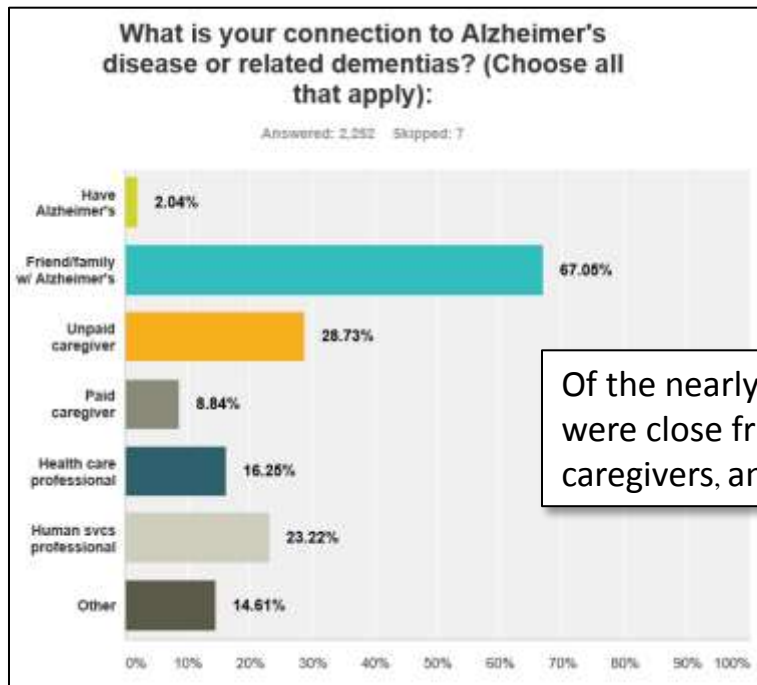
- SSB 6124 requires the Department of Social and Health Services (DSHS) to convene an Alzheimer’s disease working group, with members to be appointed by DSHS, unless indicated otherwise. The secretary of DSHS or the secretary’s designee must convene the first meeting and serve as chair of the AD working group.
- The Alzheimer’s disease (AD) working group must examine the array of needs of individuals diagnosed with AD, services available to meet these needs, and the capacity of the state and current providers to meet these and future needs.
- The AD working group must consider and make recommendations and findings on a range of specifics; and identify needed policies or responses including, but not limited to, the promotion of early detection and diagnosis of Alzheimer's disease and dementia, the provision of coordinated services and supports to persons and families living with Alzheimer's disease or dementia disorders, the capacity to meet these needs, and strategies to address identified gaps in services.
- DSHS must submit a report providing findings and recommendation of the AD working group, including any draft legislation necessary to implement the recommendations, to the governor and the health care committees of the Senate and House of Representatives by January 1, 2016.

The Alzheimer's Disease Working Group Public Survey

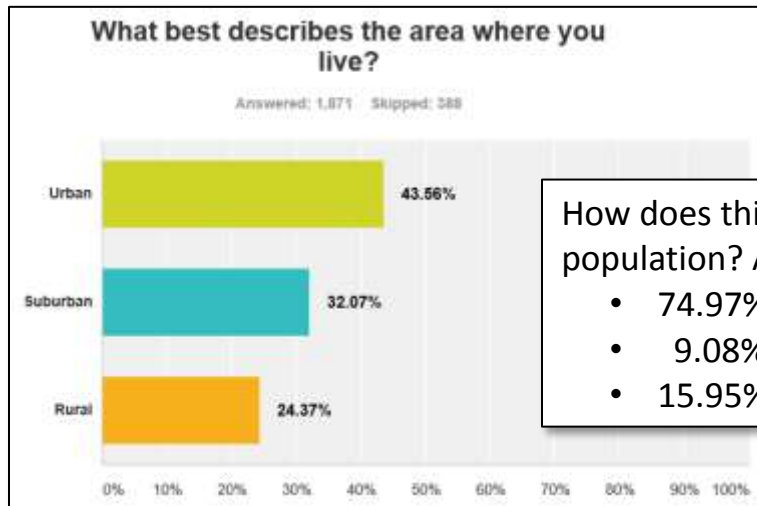
In November and December 2014, the Alzheimer's Disease Working Group (ADWG) solicited input from the public regarding their experience with Alzheimer's and other dementias. The online survey was widely distributed by members of the ADWG and their partners, other interested stakeholders, via press releases and was posted on the project web page. Over 2,250 people responded and shared their opinions and stories.

The following graphs show the results of the survey.

About the Survey Respondents



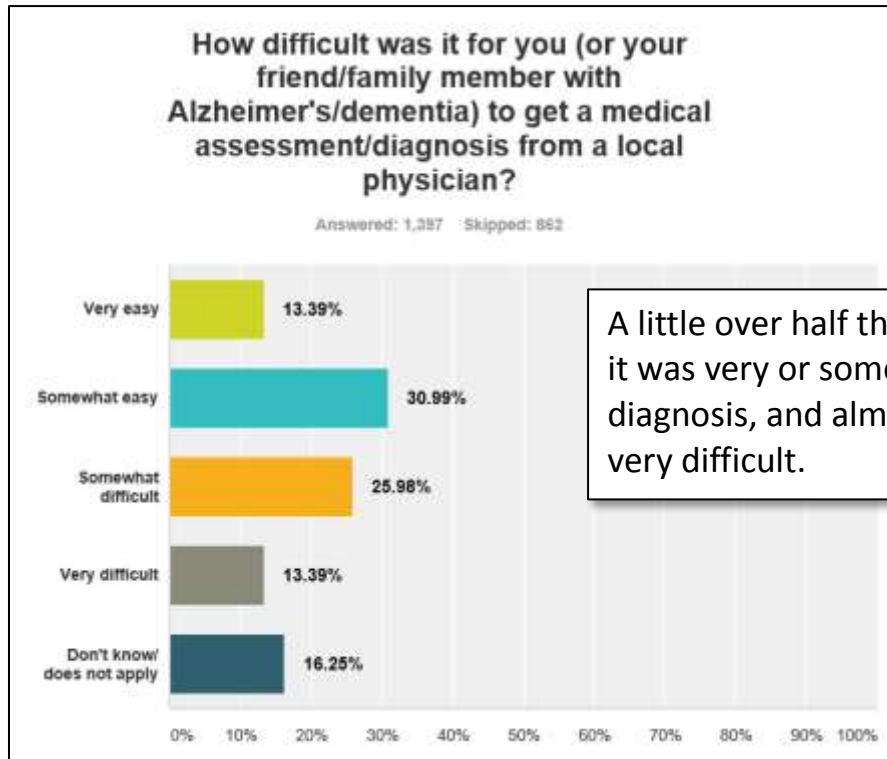
Of the nearly 2,300 respondents, over 1,500 were close friends/family, 647 were unpaid caregivers, and 46 had Alzheimer's.



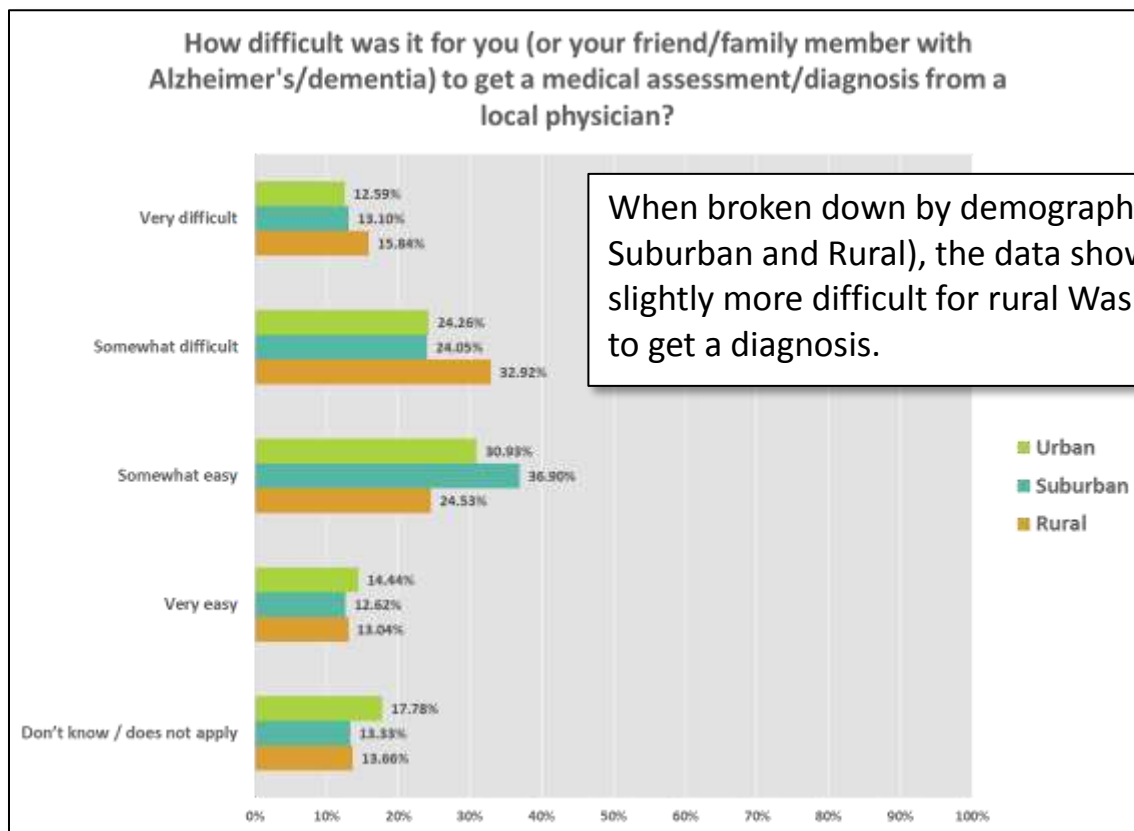
How does this compare to our state population? According to the 2010 U.S. Census,

- 74.97% of WA residents are urban
- 9.08% are suburban
- 15.95% are rural

Consumer Experience with Medical Assessment/Diagnosis



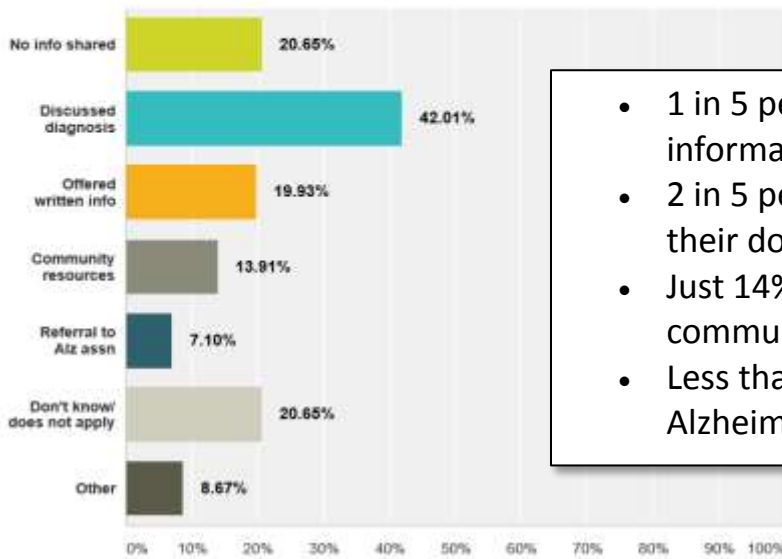
A little over half the relevant respondents said it was very or somewhat easy to get a diagnosis, and almost half said somewhat or very difficult.



When broken down by demographic (Urban, Suburban and Rural), the data shows it is slightly more difficult for rural Washingtonians to get a diagnosis.

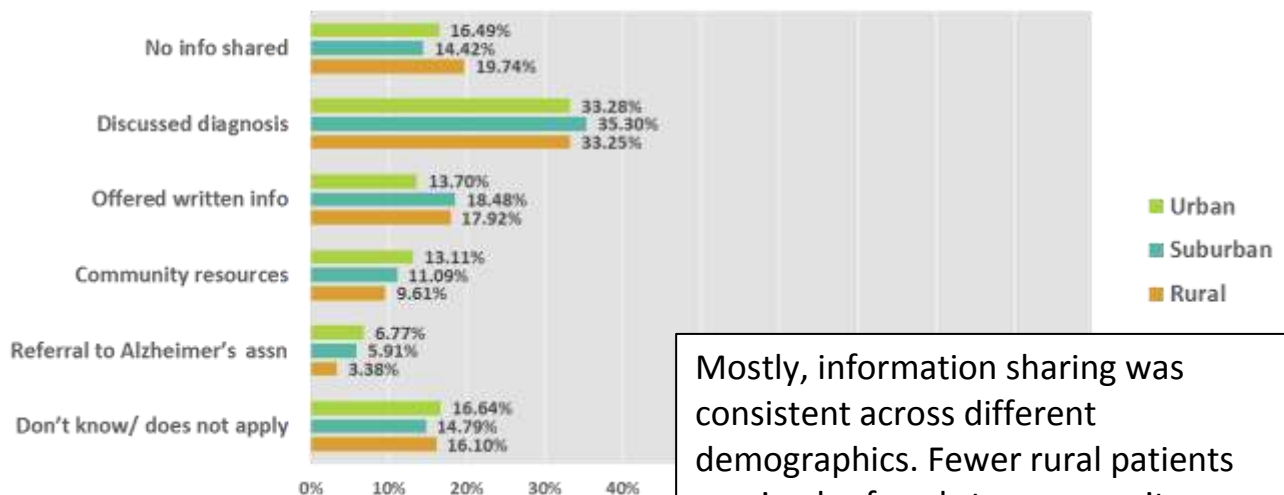
When you (or your friend/family member) were given a diagnosis of Alzheimer's or dementia, what kind of information did the provider or medical staff offer about the illness itself, planning for care, community resources or referrals? (Choose all that apply)

Answered: 1,385 Skipped: 864



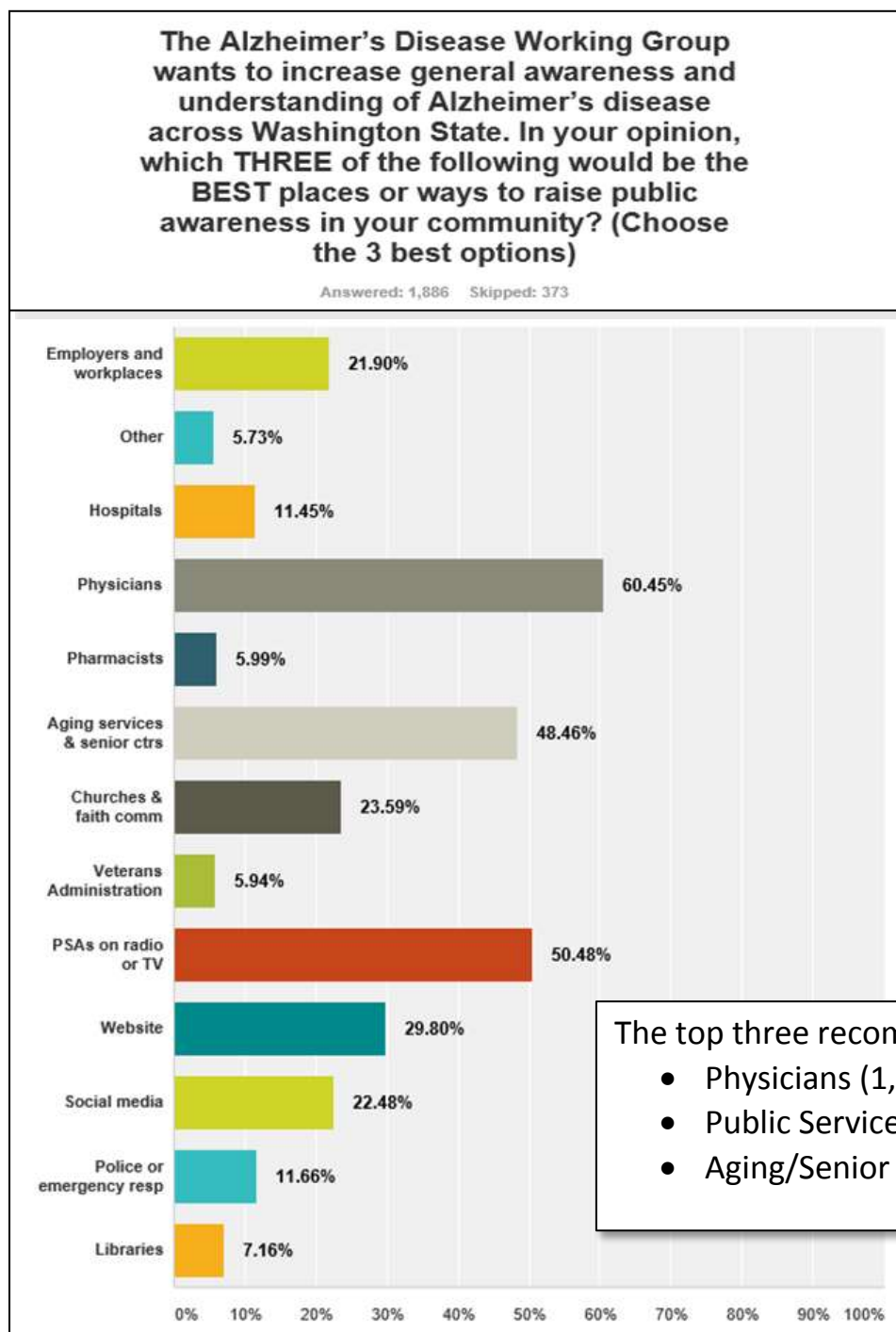
- 1 in 5 people didn't get any information about Alzheimer's.
- 2 in 5 people had a discussion with their doctor about their diagnosis.
- Just 14% received info about community resources.
- Less than 1 in 10 were referred to an Alzheimer's organization.

When you (or your friend/family member) were given a diagnosis of Alzheimer's or dementia, what kind of information did the provider or staff offer about the illness itself, planning for care, community resources or referrals? (Choose all that apply)



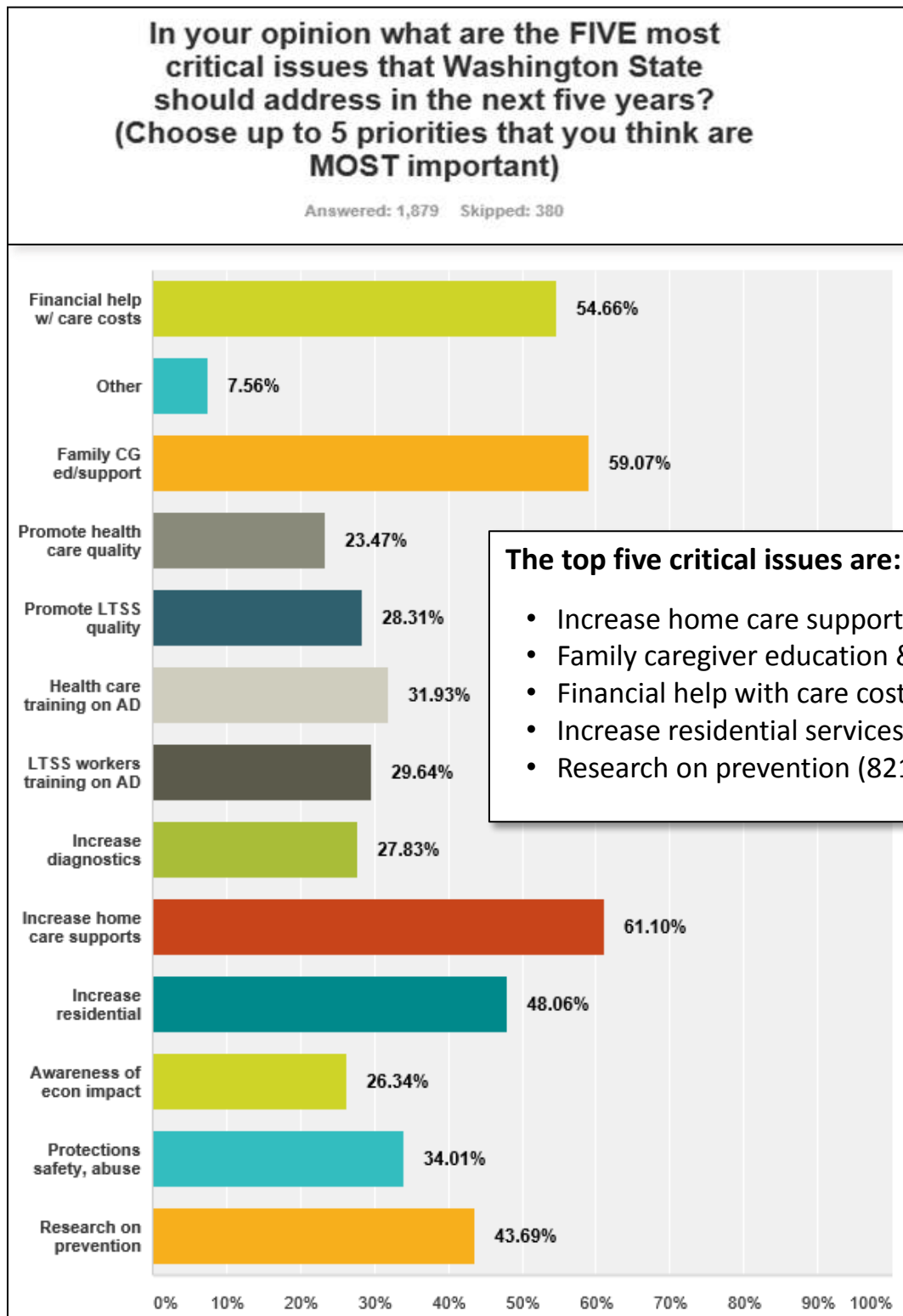
Mostly, information sharing was consistent across different demographics. Fewer rural patients received referrals to community resources/Alzheimer's organizations.

Places and Ways to Raise Public Awareness



When the data was analyzed by respondent type and by demographic, there was no difference among the groups for the top three recommendations. In other words, all respondent types and all demographics selected physicians, public service announcements and aging/senior services as their top three recommendations.

Critical Issues for Washington State



The following table shows the top five recommendations in order (plus ties) by respondent type. Four recommendations fell within the top five for all respondent types.

- Increase home care supports
- Family caregiver education & support
- Financial help with care costs
- Research on prevention

It is interesting to note that one additional recommendation, increasing availability of residential care options such as adult family homes, assisted living facilities, or specialized dementia care, was in the top five recommendations for all but one respondent type – people who have Alzheimer’s.

Table 1. Top five recommendations for the state based upon respondent type. Respondent type was determined by the response to the question, “What is your connection to Alzheimer’s disease or related dementias? (Choose all that apply).” Note that because a respondent can be in more than one group, the numbers of respondents by type add up to more than the total number of surveys.

	Friend/ Family (n=1151)	Unpaid caregiver (n=1941)	Paid caregiver (n=796)	Human services (n=524)	Health care (n=367)	Have Alzheimer’s (n=46)
1	Increase home care supports	Increase home care supports	Increase home care supports	Increase home care supports	Increase home care supports	Research on prevention
2	Family CG education/ support	Family CG education/ support	Family CG education/ support	Family CG education/ support	Family CG education/ support	Family CG education/ support
3	Financial help w/ care costs	Financial help w/ care costs	Financial help w/ care costs	Financial help w/ care costs	Increase residential	Increase home care supports
4	Increase residential	Increase residential	Health care training on AD	Increase residential	Financial help w/ care costs	Health care training on AD
5	Research on prevention	Research on prevention	Research on prevention	Research on prevention	Research on prevention	Financial help w/ care costs
			Protections safety, abuse ¹			Promote health care quality ¹

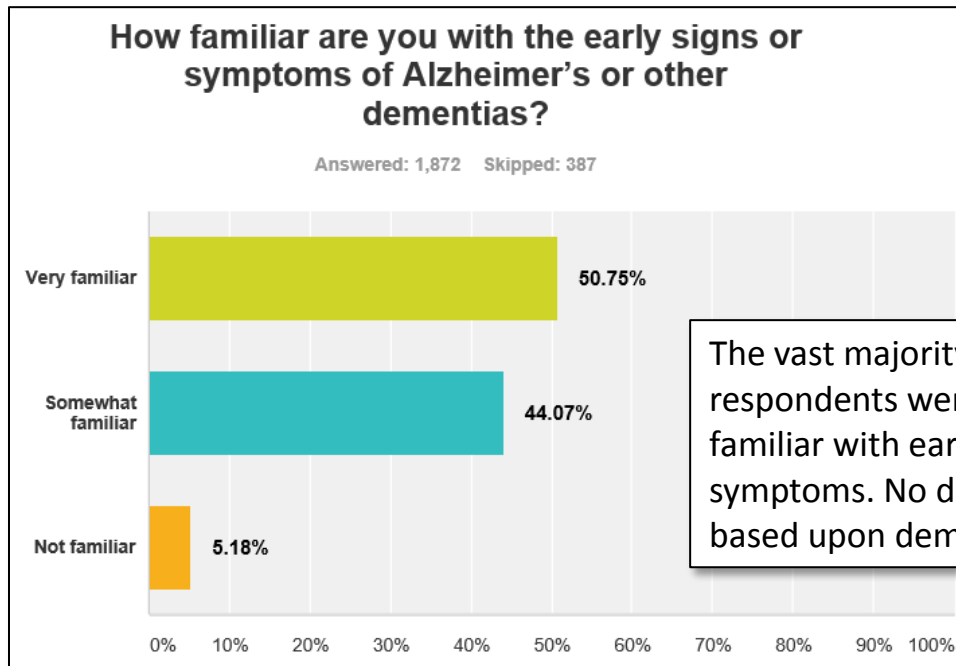
¹ Tied with 5th recommendation.

Table 2. Top five recommendations by demographic.

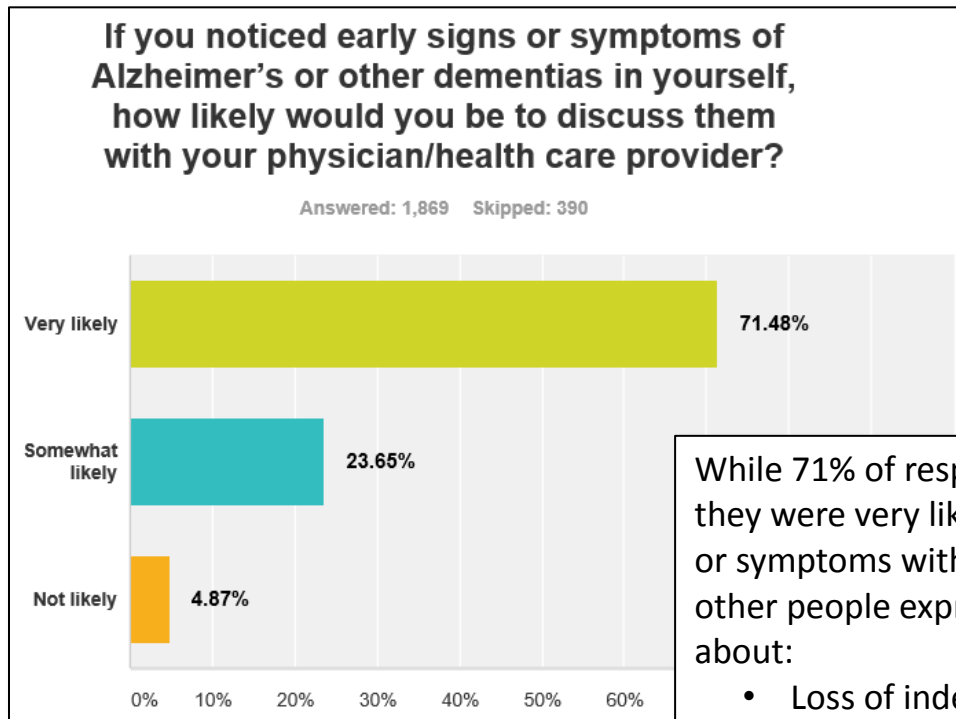
Urban (n=815)	Suburban (n=600)	Rural (n=456)
Family CG education/support	Increase home care supports	Increase home care supports
Increase home care supports	Family CG education/support	Family CG education/support
Financial help w/ care costs	Financial help w/ care costs	Financial help w/ care costs
Increase residential	Research on prevention	Increase residential
Research on prevention	Increase residential	Research on prevention

Note in the table above that all three demographics had the same top five recommendations. The only difference was the priority order.

Awareness and Attitudes about Symptoms, Assessment and Brain Health

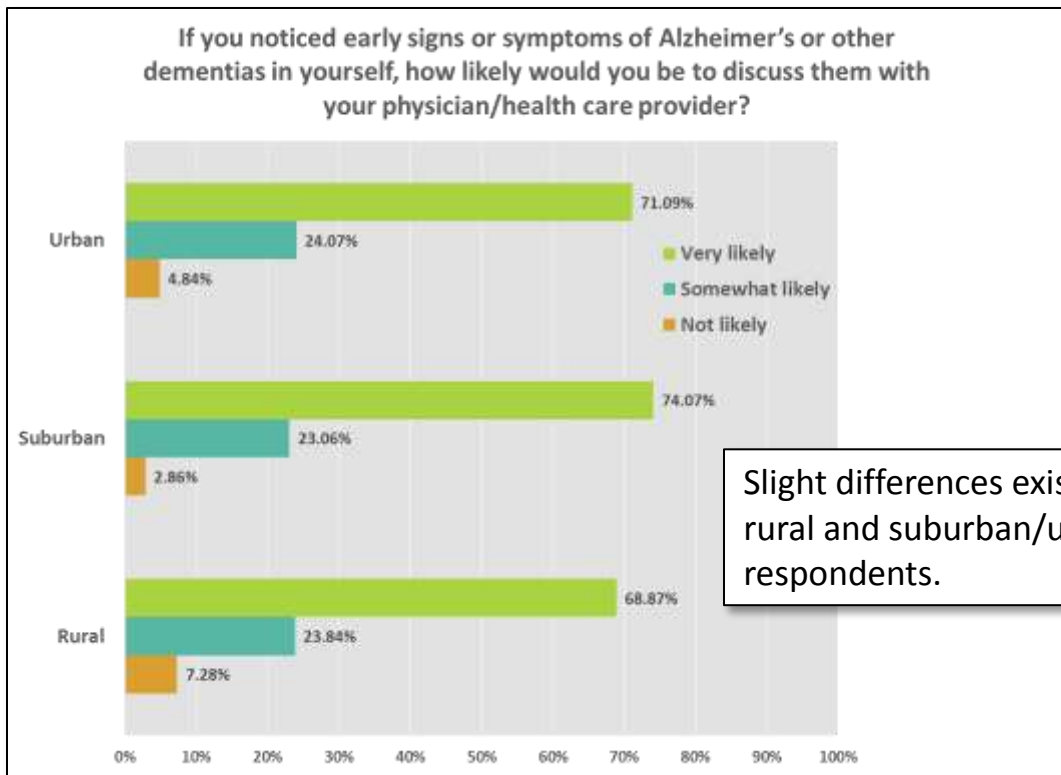


The vast majority of survey respondents were very or somewhat familiar with early signs or symptoms. No differences exist based upon demographic.

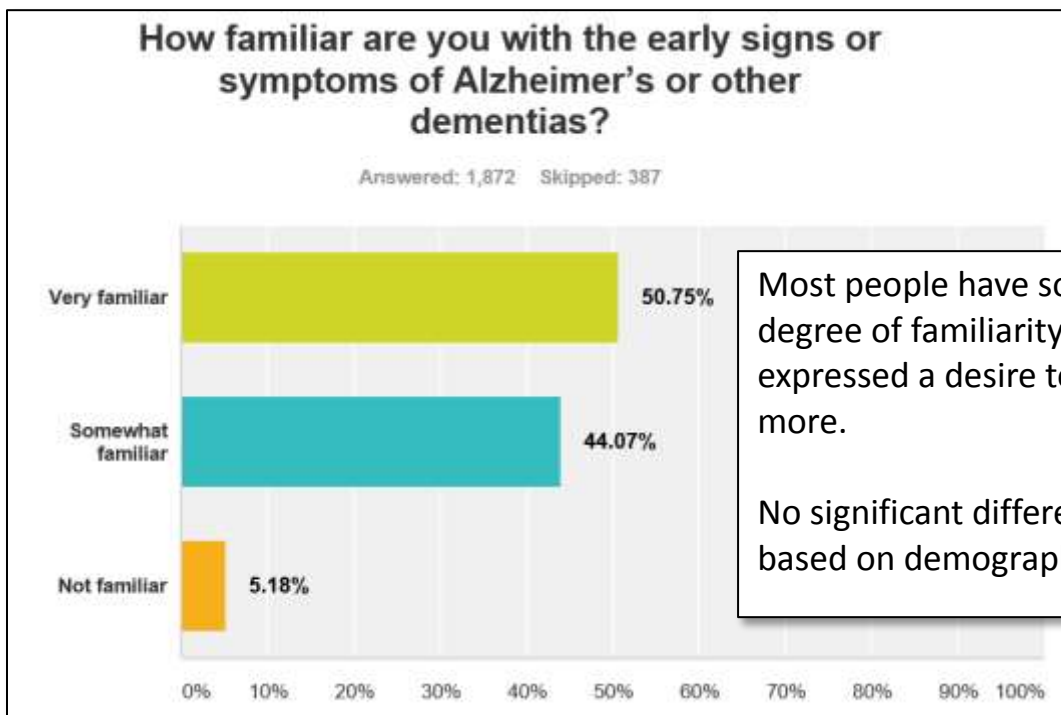


While 71% of respondents indicated they were very likely to discuss signs or symptoms with their doctor, other people expressed concerns about:

- Loss of independence
- Nothing to be done anyway
- Fear of diagnosis



Slight differences exist between rural and suburban/urban respondents.



Most people have some degree of familiarity, but expressed a desire to know more.

No significant differences exist based on demographic.

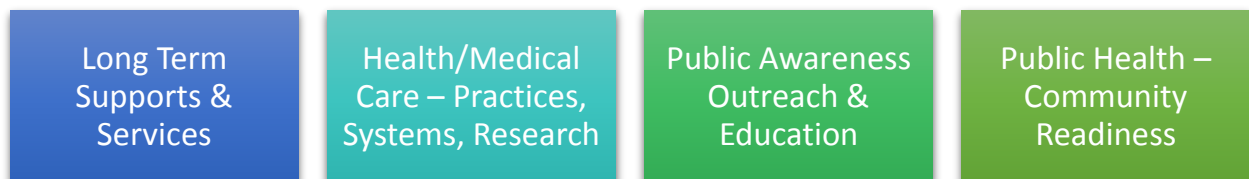
Themes from the Open-Ended Responses

Over 800 people responded to the open-ended question, “Is there anything more you would like to share about your experiences with Alzheimer’s disease or other related dementias or that you would like to see addressed in a Washington State plan related to Alzheimer’s disease or related dementias?”



Figure 1. This graphic shows a visual frequency distribution of the words used in the open-ended comments.

As part of the survey analysis, responses were categorized into four broad areas compatible with the Alzheimer's Disease Working Group subcommittees. Some comments spanned multiple categories, and were included in all relevant categories for thematic analysis.



Where sufficient data existed, themes were identified from the open-ended comments by respondent type. These themes are listed below by broad categories.

Long Term Supports and Services Themes

<p>Close Friends/Family Members (262 comments)</p>	<ul style="list-style-type: none"> • Ensure quality of life for people with Alzheimer's/dementia, including providing appropriate activities, maintaining a person's dignity and treating the person with respect. • Provide supports (respite, education, information) and payments for family caregivers. • Provide better training for caregiver staff. • People with dementia need more care and supervision than is typically assigned through the state assessment. • The financial burden of Alzheimer's on families is enormous, especially those who do not qualify for assistance. It wipes out families, and the surviving spouse has no resources remaining. Often the caregiver must leave their job to care for the person. • Services are desperately needed in rural areas. • There are deep concerns about the guardianship program. Some expressed worry that vulnerable adults with dementia are not getting guardianship services and that too few resources exist. Some expressed worry that the guardianship services are too restrictive, don't take into consideration the person's perspective, and shut out families and loved ones. • Families need an advocate who can help them navigate the complex environment of appropriate services, including understanding what's available, quality of care, and non-profit vs for-profit services.
<p>Unpaid Family Caregiver (26 comments)</p>	<ul style="list-style-type: none"> • Being a caregiver of a person with Alzheimer's/dementia is very stressful. • Caregiver support groups are helpful, but respite time is needed, even to attend them. • Often no good choices exist, and the only option is a family caregiver. Caregivers struggle to provide good support, but are often thwarted by the person or the system. • Affordable respite care is critical.
<p>Paid Caregiver Responses (38 comments)</p>	<ul style="list-style-type: none"> • Compassion and respect are important when dealing with a person with Alzheimer's/dementia. • More training is needed to help understand the progression and appropriate responses.
<p>Health Care Professional (40 comments)</p>	<ul style="list-style-type: none"> • More education for health care professionals is needed. • Prevention activities like proper nutrition and brain exercises are important throughout life.

	<ul style="list-style-type: none"> • Caregivers need significant support. • Services must be much more available and affordable. • Behaviors related to dementia must be addressed. This is often a safety concern.
Human Services Professionals (82 comments)	<ul style="list-style-type: none"> • We need more service options for people with Alzheimer's/dementia. Rural areas are especially hard-hit. • Families need help with paying for services, especially those who don't qualify for Medicaid. • Knowing what to expect and advance planning are very important. • The system pays for support with ADLs/IADLs, but people need supervision for their safety and well-being, often 24/7. • More training is necessary.
Other Respondents (101 comments)	<ul style="list-style-type: none"> • Worry that the respondent may experience dementia in the future. • Quality of life is important, and could include music or memory therapies, as well as other appropriate activities. • People with Alzheimer's/dementia are vulnerable to exploitation, and must have protections in place, including in some instances guardianship. • More training and awareness is needed. • Research and clinical trials are important.

Health/Medical Care – Practices, Systems, and Research Themes

Close Friends/Family Members (167 comments)	<ul style="list-style-type: none"> • Primary care and other clinicians need better training to understand, detect and diagnose Alzheimer's. • A typical doctor visit is often too short to deal with assessing, testing, diagnosing and discussing Alzheimer's with a person and their family. • We really need a better system for assessing driving skill and removing a person's driver's license when it is no longer safe for them to drive. • Researching a cure (or how to prevent the disease) is a critical priority. • End of life planning is especially important, and should be discussed when the person still has the ability to do so. • Clinicians should be prepared with appropriate local referrals for resources and support.
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Health Care Professional (9 comments)	<ul style="list-style-type: none"> • Each person is unique and has unique needs. There are many types of dementia. • Coordinated services must be much more available and affordable. • Behaviors related to dementia must be addressed. This is often a safety concern.
Human Services Professionals (18 comments)	<ul style="list-style-type: none"> • Early, consistent and correct diagnoses are needed. • We need more service options for people with Alzheimer's/dementia. • Medication management is important and we need to pay greater attention to the appropriate use of psychotropic drugs.
Other Respondents (10 comments)	<ul style="list-style-type: none"> • Research is critical. • There are different causes of dementia or dementia-like symptoms, some of which are temporary and can be treated. • Getting a correct and timely diagnosis is difficult.

Public Awareness, Outreach and Education Themes

Close Friends/Family Members (171 comments)	<ul style="list-style-type: none"> • We need education – general understanding of dementia, and how to interact appropriately with a person with dementia. • Local Alzheimer's Associations are important and valuable resources. • Families and advocates need to understand how to protect vulnerable people from financial and other abuse, and what steps can be taken to reduce risk. • Families need help understanding the disease progression, symptoms and behaviors associated with Alzheimer's. • The financial burden of Alzheimer's on families is enormous, especially those who do not qualify for assistance. It wipes out families, and the surviving spouse has no resources remaining. Often the caregiver must leave their job to care for the person. • Families need an advocate who can help them with long term care planning and navigate the complex environment of appropriate services, including understanding what's available, quality of care, and non-profit vs for-profit services. • Provide better training for caregiver staff, paid and unpaid.
Unpaid Family Caregiver (17 comments)	<ul style="list-style-type: none"> • Being a caregiver of a person with Alzheimer's/dementia is very stressful. • Caregiver support groups are helpful.

	<ul style="list-style-type: none"> • We all need education about Alzheimer's.
Paid Caregiver Responses <i>(8 comments)</i>	<ul style="list-style-type: none"> • The public needs more education about Alzheimer's, including some of the behavioral aspects. • Compassion and connection are important.
Health Care Professional <i>(10 comments)</i>	<ul style="list-style-type: none"> • More education about dementia is needed. • It is important to educate the public about prevention activities like proper nutrition and brain exercises. • Caregivers have a significant burden which is generally not understood by others.
Human Services Professionals <i>(19 comments)</i>	<ul style="list-style-type: none"> • Education about dementia is important for families, first responders and the general public. • Knowing what to expect and advance planning are very important.
Other Respondents <i>(28 comments)</i>	<ul style="list-style-type: none"> • More education, training and awareness are needed, for first responders, family members and the general public. • We need to make tools for informally assessing the presence of dementia available. • It is very hard to see a loved one go through the progression of Alzheimer's. • Quality of life is important, including being connected to the community in which one lives.

Public Health – Community Readiness Themes

Close Friends/Family Members <i>(53 comments)</i>	<ul style="list-style-type: none"> • We need a better system for assessing driving capabilities and managing driver's licenses. • We need to de-stigmatize dementia. • Access to care and health disparities among various populations needs to be addressed. • The financial burden for care for families who are not very poor or very rich is disproportionately difficult to manage. • Educate young people about Alzheimer's and other dementias. • We need to address prevention strategies. • We need a Silver Alert system, similar to the Amber Alert system. • Tribes in WA State should be involved in this dialog.
Unpaid Family Caregiver <i>(7 comments)</i>	<ul style="list-style-type: none"> • De-stigmatize dementia, seek testing early. • First responder network (Police, Fire, EMS) is a critically valuable support to families, and we need to work together.

	<ul style="list-style-type: none"> • Understand the potential triggers and steps to reduce risk of developing Alzheimer's.
Health Care Professional (4 comments)	<ul style="list-style-type: none"> • Early awareness is critical.
Human Services Professionals (9 comments)	<ul style="list-style-type: none"> • We need "dementia-friendly" communities. • Advance planning is important. • An alert system is needed.
Other Respondents (5 comments)	<ul style="list-style-type: none"> • Prevention and community building are important.

Alzheimer's Disease Working Group [webpage](#):

<https://www.dshs.wa.gov/altsa/stakeholders/developing-state-plan-address-alzheimers-disease>

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